# **AHRQ Grant Final Progress Report**

Title of Project: Improving Outpatient Safety of Older Adults through Electronic Patient Portals

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#### 1. Structured Abstract

**Purpose:** The purpose of this study was to assess whether providing caregivers of older adults proxy access to an electronic patient portal (EPP) improves the outpatient medication safety and communication between caregivers and healthcare providers. We also examined the content of EPP messages from older adult patients and their caregivers in order identify how the EPP was used

**Scope:** This study included older adult general internal medicine/geriatrics patients and their caregivers.

**Methods:** In study aims 1-3, a convenience sample of patients and their caregivers at an outpatient internal medicine/geriatrics clinic participated in the study. In study aim 4, a cross-sectional, single-center retrospective chart review of older adult patients and their caregivers was conducted.

**Results:** EPP access for caregivers increased the information exchange between caregivers and health care providers at 2-weeks. There was no correlation with predictors of EPP use for patients who live in multiple settings in one year. Barriers to EPP use included: password issues, being too busy, not receiving prompt responses from providers and trouble reading the small print on the EPP messages. Nonetheless, patients 85 years and older and their caregivers readily utilized the EPP to facilitate care. On average, 9.9 messages (n=576) were sent by 62 patients and 82 caregivers (n=678, mean 7.8) in a six-month period. We observed no differences in the content type of EPP message/content when comparing messages from older adult patients and caregivers.

**Key Words:** electronic patient portals, electronic medical record, health IT, patient-provider communication, caregivers

#### 2. Purpose

The purpose of this study was to assess whether providing caregivers of older adults proxy access to an Electronic Patient Portal (EPP) would improve the outpatient medication safety and communication between caregivers and health care providers. The specific aims of the study were as follows:

**Aim 1:** Investigate whether Electronic Patient Portal (EPP) usage by caregivers facilitates the accuracy of outpatient medication reconciliation and health care provider communication.

H1: Accessing the physician medication list from the home will allow for caregiverspatients to improve the accuracy of the medications in the medical record list (e.g. medications no longer being taken, medications being taken but not present on the list).

**H2:** EPP access will increase the information exchange between caregivers and health care providers (e.g., condition updates, questions about care).

**Aim 2:** Identify caregiver and older adult patient characteristics that correlate with usage and non-usage of EPP (e.g. patient lives in different residences during the year, number of medications, complex medical history).

**H1:** Older adults who live in more than one setting (e.g. winter in Florida) will have caregivers who access the EPP more frequently.

**H2:** Caregivers who care for older adults with more complex medical histories and multiple medications will access the EPP more frequently.

**Aim 3:** Determine barriers to EPP usage among caregivers of older adults and potential means of improving the accessibility and usability of EPPs.

**Aim 4:** Explore the content of EPP messages from caregivers of older adults to providers in order identify what the EPP is most being used for (e.g. medication questions, hospitalization updates, appointments, etc.).

# 3. Scope

# A. Background

Electronic personal health records (ePHRs) provide an Internet-based set of tools for individuals "to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it." There are two basic ePHRs: one that is "tethered" to the health care provider's electronic health record (EHR) and one that is "untethered" and is independent of the EHR. Tethered ePHRs, which are also referred to as electronic patient portals (EPPs), vary in their capabilities, but most allow patients to engage in healthcare-related tasks such as sending secure messages to providers, reviewing test results, refilling medications, and occasionally participating in online disease management programs. PPPs also enable patients to access their electronic health record information 24 hours a day, 7 days a week. For example, secure messaging allows for asynchronous communication between patients and providers. This function may decrease the threshold for communication and increase substantive communication about health management. Enhanced communication, in turn, may lead to improved patient experiences with their health care and an increased desire to engage in one's own healthcare (i.e., activation). Many functions, such as secure messaging, medication refills and scheduling, may increase efficiency of care by reducing the need for time and resource intensive 'phone tag.'

The Impact of Electronic Patient Portals on Health Outcomes and Medications. EPPs are an innovative means of encouraging patient participation in their care, and have the potential to improve health outcomes. See Research has demonstrated that EPPs are associated with increased patient satisfaction when they provide access to office notes and secure messaging with providers. Interventions through the EPP have been shown to increase use of recommended preventive services and improved control of chronic diseases such as diabetes. EPPs may also enhance safety through improved access to medication lists and laboratory results.

A persistent issue has been that medication lists in EHRs are frequently inaccurate which impairs outpatient medication safety. With complex medical histories and multiple subspecialty providers, older adults experience frequent medication additions and changes. Subsequently, older adults face more medication errors than their younger counterparts. With EPP access, patients have the ability to access their EHR medication lists from home and correct them while holding the pill bottles as needed, even reconciling medications between providers.

Disparities among Older Adults using Electronic Patient Portals between Providers.

Older adults have been on the fringe of benefitting from EPP access. Many seniors, at baseline, lack computer savvy. 30-34 Compounded by memory loss and other impairments, older adults may need to rely on others to assist them with their healthcare. 35-37 Instead of removing older adults from the possibility of EPP use, caregivers could be offered the use of EPP instead. In pediatrics, parents have successfully used EPPs to care for their children as surrogates. 38,39 Older adults and their powers of attorneys (where enacted) would have to consent in order for this access to be permitted. 40,41

Many Older Adults Rely on Caregivers to Stay Healthy in their own Homes. It is estimated that there are over 46 million caregivers nationally, with 83% of caregivers providing care for relatives. 42-44 Caregivers are frequently responsible for health-related tasks such as medication reminding, prescription refilling, scheduling physician appointments, and communicating condition updates with the health care team. 45-52 However, the training and support that caregivers receive is limited. 53-59

Caregivers Access the Internet to Educate Themselves on Senior Care.

Caregivers have historically accessed web-based material for general disease specific information relevant to seniors. While these websites offer useful information, there is a lack of information personalized to the health care of the senior. Websites aimed to support caregivers of older adults, such as the Family Caregiver Alliance (www.caregiver.org), National Family Caregivers Association (www.nfcacares.org), and AARP (www.aarp.org/families/caregiving), receive widespread use. Caregivinghelp.org, a website created by the Council of Jewish Elderly, experiences prominent activity in the evening and late night hours. Caregivers are finding the internet a useful resource, not only for content but also because of its availability at all hours. With the internet, caregivers can access resources at night when most physician offices and stores are closed, but when their seniors are sleeping.

## B. Context, Settings

This project focused on older adult patients with at least one caregiver, receiving care at the Northwestern Medicine outpatient internal medicine/geriatrics clinic in Chicago, Illinois. The practice has approximately 40 health care providers and uses the Epic MyChart electronic health record and patient portal system.

## C. Participants

In study aims 1-3, study participants included older adult patient-caregiver pairs of patients receiving care at the Northwestern Medicine outpatient internal medicine/geriatrics clinic who were at least 65 years of age. Prior to enrolling in the study, patients were not currently registered with an Epic MyChart EPP. Caregivers enrolled in the study as a pair were at least 18 years old, had Internet access, and assisted their older adult patient with their medications and communication with the healthcare team. In study aim 4, study participants included in the retrospective chart review analysis were older adult patients age 85 and older who received care at the outpatient internal medicine/geriatrics clinic from July 1, 2016 – December 31, 2016, and had a registered MyChart EPP account.

## 4. Methods

## A. Study Design

Overall, the study employed the Behavioral Model of Health Services Use that stresses understanding of health services use was best accomplished by focusing on contextual and individual determinants as a framework <sup>66-68</sup>. Contextual characteristics include health organization, provider-related factors, and community characteristics. For individual determinants, a three-part conceptual framework emphasizes predisposing factors, need, and enabling resources. <sup>69</sup> With health services utilization and the care of seniors, key determinants are (1) predisposing factors such as the caregiver education and concern for the senior, (2) need for the complicated senior to receive optimal home care and (3) enabling resources, such as access to health information. EPP access to the EHR would enable caregivers accessing health information, playing an integral role in caregiver health education and understanding. The Behavioral Model of Health Services Use supports the caregiver use of EPP access to EHR could play a vital role in educating caregivers and improving the care of seniors in the home.

In study aims 1-3, we utilized a convenience sample where participants were recruited in person at the Northwestern Medicine outpatient internal medicine/geriatrics clinic, met the study eligibility criteria, and consented to participate in the study. In study aim 4, a cross-sectional, single-center retrospective chart review of older adult patients and their caregivers was conducted.

#### B. Data Collection/Sources

In study aims 1-3, following informed consent and enrollment in the study, face-to-face structured interviews were performed with both the senior and caregiver (caregiver was given option to complete surveys online) to collect self-reported data that included socio-demographic questions, cognitive function assessments, health literacy assessments, and qualitative data regarding EPP use. This was done at baseline, 2-weeks post baseline, and a four-month follow-up interview. Study data were collected and managed using REDCap electronic data capture tools hosted at Northwestern University. REDCap is a secure, Web-based application designed to support data capture for research studies. Patient comorbidity, medication, and patient/caregiver MyChart communication history were extracted from the Northwestern Medicine Enterprise Data Warehouse (EDW). A signed consent form was obtained for each participant and each subject received compensation for each of the surveys completed at the various time points.

In study aim 4, a retrospective chart review was conducted on all patients meeting the established criteria for the data query. Participant demographics, comorbidity, medication, and MyChart patient-physician communication history data (all relevant data including log-ins, messaging, and phone calls) were extracted from the EDW.

#### C. Interventions

In study aims 1-3, patients were enrolled in the EPP (MyChart) by the study coordinator and with patient consent, their caregiver was given proxy access to the EPP and they too were shown how to use the EPP. Patient-caregiver pairs enrolled in the study were each asked to complete a series of surveys at various time points. Each patient and caregiver completed individual surveys. The first survey was completed on the day of enrollment (baseline) where patients completed it in person, and caregivers completed the survey in-person or online. Subsequent surveys for study

participants were conducted at 2-weeks and 4-months post-enrollment and were carried out either over the phone or online, based on their preference. Data was collected both by self-report at the data collection time points and also included patient data abstraction from the EDW to assess patient-physician communication history data and confirm medication and comorbidity information. In study aim 4, no intervention was carried out since this was a retrospective chart review with no patient or caregiver interaction or intervention.

#### D. Measures

**Time Points:** For data extracted from the EPP for study Aims 1-3, we defined the pre-period for the 2-week assessment as 2-weeks prior to enrollment in the study (e.g. 2-weeks prior to enrollment to baseline). The post period is defined as 2-weeks after enrollment (e.g. baseline to 2-weeks post-enrollment). The 4-month assessment pre-period was defined as 2-weeks prior to the four-month post-enrollment period. The post period is defined as 2-weeks after the four-month post-enrollment period.

Comorbidities/Self-Reported Physical Health: We did not use the geriatric comorbidity index due to difficulties with implementation. Instead we used patient's self-reported physical health as an indicator of medical complexity. Self-rated health was captured on a 5-point scale and collapsed into three groups (Fair/Poor, Good, Very Good/Excellent) with Good as the reference group.

**Health Literacy:** Initially we used the Short Test of Functional Health Literacy in Adults (STOFHLA) as the measure of health literacy which consists of 36 items and distributes individuals to three levels of health literacy: inadequate (score 0-16), marginal (score 17-22) and adequate (23-36) health literacy. However due to time of the surveys being cited as a barrier to enrolling in the study by multiple patients' feedback, we revised the protocol to use the Rapid Estimate of Adult Literacy in Medicine—Short Form (REALM-SF) which is a 7-item word recognition test to provide clinicians with a valid quick assessment of patient health literacy. It categorizes participants into four various levels depending on the score:

Score	Grade Range
0	Third grade and below; will not be able to read most low-literacy materials; will need repeated
	oral instructions, materials composed primarily of illustrations, or audio or video tapes.
1-3	Fourth to sixth grade; will need low-literacy materials, may not be able to read prescription
	labels.
4-6	Seventh to eighth grade; will struggle with most patient education materials; will not be
	offended by low-literacy materials.
7	High school; will be able to read most patient education materials.

Ultimately we did not use or analyze health literacy due to issues with different instruments being used, missing data, and low variability.

#### E. Limitations

There were several limitations related to study aims 1-3. We did not have access to baseline data for self-reported medication reconciliation, therefore we only obtained this information at 2-

weeks post enrollment. Consequently, we were unable to carry out the proposed statistical testing related to medication reconciliation. We were also unable to analyze health literacy as a covariate due to issues with different instruments being used, missing data, and low variability.

Another limitation in study aim 4 is that the study population may not be representative of all older adult patients and caregivers who may not have facility with EPPs due to varying health conditions and/or limited computer literacy.

## **Results**

Results are associated with each of the study aims and are a set of one or more specific hypotheses investigated.

Overall, 30 patient-caregiver pairs (N=60) were recruited into this study and their data were analyzed for study Aims 1-3. The completion and follow-up rate for the patient-caregiver pairs by time point is reflected below:

Table 1: Patient and Caregiver Survey Completion and Follow-Up Rate

	]	Patients	Caregivers		
	N	%	N	%	
Screener	30	100.0	30	100.0	
Baseline	30	100.0	27	90.0	
2-week follow up	25	83.3	20	66.7	
4-month follow up	13	43.3	18	60.0	

The patient and caregiver demographics for the study participants are shown in Table 2.

Table 2: Patient and caregiver demographics

	Pati	ents	Caregivers	
	N	%	N	%
Overall	30	-	27	-
Age, mean (sd)	84.4	7.0	59.4	10.0
Sex				
Male	7	23.3	8	29.6
Female	23	76.7	19	70.4
Race/Ethnicity				
Non-Hispanic White	18	60.0	13	48.1
Non-Hispanic Black or African American	10	33.3	9	33.3
Hispanic/Latino	1	3.3	1	3.7
Non-Hispanic Asian	1	3.3	1	3.7
Non-Hispanic American Indian/Alaska Native	0	0	1	3.7
More than One Race	0	0	2	7.4
Country of birth				
United States	25	83.3	24	88.9
Other	5	16.7	3	11.1
Marital status				
Single, never married	0	0	5	18.5
Married	11	36.7	14	51.9

	Patients		Care	givers
	N	%	N	%
Widowed	12	40.0	2	7.4
Divorced/separated	7	23.3	5	18.5
Prefer not to say	0	0	1	3.7
Live alone?				
Alone	12	40.0	6	22.2
With at least one other person	18	60.0	21	77.8

	Pati	ents	Care	givers
	N	%	N	%
Employment status				
Retired	28	93.3	9	33.3
Employed full-time	2	6.7	11	40.7
Self-employed	0	0	4	14.8
Unemployed - out of work > 1 year	0	0	2	7.4
Homemaker	0	0	1	3.7
Education				
Grades 1 through 8 (Elementary)	1	3.3	0	0
Grades 9 through 11 (Some high school)	1	3.3	0	0
Grade 12 or GED (High school graduate	7	23.3	0	0
College 1 year to 3 years (Some college)	7	23.3	7	25.9
College 4 years (College graduate)	5	16.7	7	25.9
Graduate school (Advanced degree)	9	30.0	13	48.1
Personal Income				
Less than \$20,000	1	3.3	0	0
\$20,000-\$40,000	6	20.0	0	0
\$40,001-\$60,000	6	20.0	1	3.7
\$60,001-\$80,000	1	3.3	5	18.5
\$80,001-\$100,000	5	16.7	1	3.7
More than \$100,000	3	10.0	9	33.3
Don't know/Not sure	5	16.7	1	3.7
Prefer not to say	3	10.0	10	37.0
Self-rated physical health				
Excellent	2	6.7	6	22.2
Very good	9	30.0	11	40.7
Good	12	40.0	6	22.2
Fair	5	16.7	4	14.8
Poor	2	6.7	0	0
Self-rated physical mental health				
Excellent	3	10.0	8	29.6
Very good	6	20.0	7	25.9
Good	12	40.0	8	29.6
Fair	8	26.7	4	14.8
Poor	1	3.3	0	0

The following are the principal findings and outcomes by aim and hypothesis:

Aim 1, Hypothesis 1 (medication reconciliation pre/post): Seven caregivers (63.6%) reported checking the patient medication logs, and among those who did, six (85.7%) reported no discrepancies (one did not know). Statistical testing was not completed as there was no pre/post data available (self-reported medication reconciliation data are only available at 2-week follow up).

Aim 1, Hypothesis 2 (communication pre/post): Communication (over phone or EPP messages) between caregivers and health care providers increased from the 2-week pre-period data (43.3%) to the 2-week post-period data (66.7%). We did not see a change in the communication exchange between caregivers and healthcare providers between the four-month pre-and post-period.

Table 3: Any communication between caregivers, healthcare providers (Aim 1)

	Pre		Post			
	N	%	N	%	P Value	
2 Week	13	43.3	20	66.7	0.0348	
4 Month	26	86.7	26	86.7	1.000	

P values were calculated using McNemar's test of quality of paired proportions (e.g. comparing any messages during 2 week pre-period data to any messages during 2 week post-period data for the same individual).

EPP access for caregivers increased the information exchange between caregivers and health care providers at 2-weeks (p=0.03) but was not statistically significant at 4-months.

We also examined the communication counts (number of phone calls + EPP messages) to assess whether communication volume increased between caregivers and health care providers:

Table 4: Communication frequency between caregivers, healthcare providers (Aim 1)

	Pre			P	ost		
	Mean	Std Dev	Median	Mean	Std Dev	Median	P Value
2 Week	1.0	1.8	0	1.8	2.0	1	0.0942
4 Month	6.1	9.0	2.5	8.7	12.8	5.5	0.0950

P values calculated using Wilcoxon singed-rank test of mean ranks of paired pre/post data (e.g. comparing 2 week pre-period communication counts to 2 week post-period communication counts for the same individual).

EPP access for caregivers did not significantly increase the total amount of communication either at the 2-week follow-up or the 4-month follow-up period.

## Aim 2 Hypothesis 1 (predictors of EPP use including multiple settings):

We examined the data to identify if any caregiver and older adult patient characteristics correlated with usage or non-usage of the EPP. Hypothesis 1 specifically looked to see if older adults who lived in more than one setting in a year had caregivers who accessed the EPP more frequently. We observed this data at 2-weeks and four-months post enrollment. Almost half (46.7%) of patients reported living away from home at least one week during the year.

For logistic regression models, we did not use health literacy due to issues with different instruments being used, missing data, and low variability. An unadjusted model used a single predictor (whether the senior is away at least one week during the year). An adjusted model added covariates for caregiver age and caregiver gender.

Table 5: 2 Week Results, Logistic Regression, Any EPP logins predicted by living in multiple settings and covariates (Aim 2)

	Senior Away at least one week		Caregiver Age (years)		Caregiver Female	
	during year					
Model	Odds Ratio	P Value	Odds Ratio	P Value	Odds Ratio	P Value
	(95% CI)		(95% CI)		(95% CI)	
Unadjusted	0.6(0.1-2.9)	0.5246	-	-	-	-
Adjusted	0.3 (<0.1 – 2.4)	0.2618	1.0(0.9-1.1)	0.5483	1.3(0.2-10.5)	0.8138

Older adults living in more than one setting at least one week during the year did not have caregivers who accessed the EPP more frequently in the 2-week follow-up period than those who did not report living in multiple settings. We did not find any correlation with predictors of EPP use for patients who live in multiple settings during the year.

Table 6: 4 Month Results, Logistic Regression, Any EPP logins sent predicted by living in multiple settings and covariates (Aim 2)

	Senior Away at least one week during year		Caregiver Age	(years)	Caregiver Female	
Model	Odds Ratio (95% CI)	P Value	Odds Ratio (95% CI)	P Value	Odds Ratio (95% CI)	P Value
Unadjusted	0.6(0.1-3.2)	0.5282	-	-	-	-
Adjusted	0.3 (<0.1 – 3.0)	0.2905	1.0(08-1.1)	0.6485	1.0(0.1-12.4)	0.9870

We found that older adults living in more than one setting at least one week during the year did not access the EPP more frequently in the 4-month follow-up period than those who did not report living in multiple settings.

We also ran an alternate version of the same analysis using EPP messaging as the outcome since it's more strongly tied to active use of the EPP than simply logging in at all (and thus less prone to effects of test logins, etc.).

Table 7: 2 Week Results, Logistic Regression, Any EPP message sent predicted by living in multiple settings and covariates (caregiver age, caregiver gender)

	Senior Away at least one week during year		Caregiver Ag	ge (years)	Caregiver Female	
Model	Odds Ratio (95% CI)	P Value	Odds Ratio (95% CI)	P Value	Odds Ratio (95% CI)	P Value
Unadjusted	0.1 (<0.1 – 1.2)	0.0764	-	-	-	-
Adjusted	0.1 (<0.1 – 0.9)	0.0392	1.0 (0.9-1.1)	0.6270	8.8 (0.3 – 222.4)	0.1873

In unadjusted analysis, there was no difference in odds of at least one EPP message being sent within two weeks between seniors who live in multiple settings and those who do not. After adjusting for caregiver age and caregiver gender, seniors who live in multiple settings were less likely to have had at least one EPP message sent (p=0.0392).

Table 8: 4 Month Results, Logistic Regression, Any EPP message sent predicted by living in multiple settings and covariates

	Patient away at least one week during year		Caregiver A	Age (years)	Caregiver Female	
Model	Odds Ratio (95% CI)	P Value	Odds Ratio (95% CI)	P Value	Odds Ratio (95% CI)	P Value
Unadjusted	0.2 (<0.1 – 1.1)	0.0597	-	-	-	-

Adjusted 0.1 (<0.1 – 0.9)	0.0379	0.9 (0.9-1.0)	0.2564	4.7 (0.4 – 60.6)	0.2310
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In unadjusted analysis, there was no difference in odds of at least one EPP message being sent within four months between seniors who live in multiple settings and those who do not. After adjusting for caregiver age and caregiver gender, seniors who live in multiple settings were less likely to have had at least one EPP message sent (p=0.0379).

## Aim 2 Hypothesis 2 (predictors of EPP use for medication management):

We examined whether caregivers who care for older adult patients with more complex medical histories and multiple medications accessed the EPP more frequently.

We did not use health literacy due to issues with different instruments being used, missing data, and low variability. We did not use the geriatric comorbidity index due to difficulties with implementation. Instead we used patient's self-reported physical health as an indicator of medical complexity and count of baseline medications (EHR-derived data tallying unique simple generic names). Self-rated health was captured on a 5-point scale and collapsed into three groups (Fair/Poor, Good, Very Good/Excellent) with Good as the reference group. Patient residence was also used as a predictor (house, apartment, senior community) with house as the referent. The logistic regression models revealed the following at 2- and 4-month follow-up points:

Table 9: 2-Week Results, Logistic Regression, Any EPP messages sent predicted by medication count and covariates (Aim 2)

For each additional medication on a patient's medication list, the odds of having at least one EPP message sent at two weeks was 1.26 greater in unadjusted analysis. This increase remained significant after adjusting for caregiver age, caregiver gender and senior residence (three categories described above). When additionally adjusting for senior self-rated physical health, the increased odds were not statistically significant.

Table 10: 4-Month Results, Logistic Regression, Any EPP logins sent predicted by living in multiple settings and covariates (Aim 2)

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Model	Odds Ratio (95% CI)
Unadjusted	1.26 (1.02 – 1.56)
Adjusted #1: CG age, CG gender, Senior	1.62 (1.05 – 2.51)
residence	
Adjusted #2: CG age, CG gender, Senior	1.52(0.86-2.72)
residence, senior self-rated physical	
health	
Model	Odds Ratio (95% CI)
Model Unadjusted	Odds Ratio (95% CI)  1.34 (1.04-1.73)
	` /
Unadjusted	1.34 (1.04-1.73)
Unadjusted Adjusted #1: CG age, CG gender, Senior	1.34 (1.04-1.73)
Unadjusted Adjusted #1: CG age, CG gender, Senior residence	1.34 (1.04-1.73) 1.43 (1.01-2.02)

We found that for each additional medication on a patient's medication list, the odds of having at least one EPP message sent at four months was 1.34 greater in unadjusted analysis. This increase remained significant after adjusting for caregiver age, caregiver gender and senior residence (three categories described above). When additionally adjusting for senior self-rated physical health, the increased odds were not statistically significant.

# Aim 3: Determine barriers to EPP usage among caregivers of older adults and potential means of improving the accessibility and usability of EPPs.

At both the 2-week follow-up interview and the 4-month follow-up interview, we asked caregivers about their EPP access during those time points. At 2-weeks post-baseline 20 caregivers responded to the survey and 55% (n=11) of caregivers reported logging onto the EPP. At four-months, a total of 18 caregivers responded to the survey with 72.2% (n=13) reported logging onto the EPP.

For those that did not log on to the EPP, we ascertained barriers to their EPP use. We coded the responses and found their barriers to use included: password issues, not needing to log in during that time period, being too busy, not getting prompt responses from their providers when they sent messages on the EPP, and trouble reading the small print.

When asked how the EPP could be improved, particularly to help address their barriers, users suggested ensuring that health care providers are not only using EPP, but that they are also responding to messages and requests in a timely manner. Users also suggested increasing the print size of the EPP, especially on mobile devices.

Aim 4: To explore the content of EPP messages from caregivers of older adults to providers in order identify what the EPP is most being used for (e.g. medication questions, hospitalization updates, appointments, etc.).

We report the results for the four parts of this mixed-methods analysis below.

Part 1 (EPP use differentiated by medical conditions): We used cross-sectional (observational) EHR data from problem lists and medical history of queried patients to see if patients who had congestive heart failure (CHF), coronary arterial disease (CAD) and/or Alzheimer's disease (ALZ) had caregivers who used the EPP more frequently than those caregivers for patients that did not have these conditions.

Table 11: 6-Month EPP utilization for messaging (Aim 4)

	Any EPP		No EPP		P	Number o	of EPP	P
	Messages	Sent	Messages Sent		value*	value* Messages Sent		value**
	N	%	N	%		Mean	SD	
CHF, CAD and/or ALZ					0.0112			0.2514
Yes	79	30.7	178	69.3		2.45	7.67	
No	77	21.6	280	78.4		1.79	6.03	

<sup>\*</sup>P value calculated using chi-squared test for difference EPP messages sent (Yes/No) across medical conditions.

Almost one third (30.7%) of patients who had a medical history of either CHF, CAD, and/or ALZ had caregivers that sent <u>any</u> messages through the EPP during the six-month queried period compared to 21.6% of patients who did not have any of these conditions in their medical history. This difference was statistically significant (p=0.01). We did not observe a difference between the numbers of EPP messages sent by caregivers of patients across medical conditions.

# Aim 4, Part 2 (difference in EPP messages types between patients & caregivers):

We analyzed the EPP message content during the 6-month period to see if there was a difference in EPP message type/content between caregivers and patients. There were 614 patients included in the datasets, among whom 145 sent one or more EPP messages (mean 8.65 messages per patient among this subset).

Table 12: EPP message content, by type (Aim 4)

	Messages Sent	Among all Patients (n=614)		Patients Sending Messages for this Reason	Among Patients Sending Messages for this Reason	
	N	Mean	SD	N	Mean	SD
EPP Message Reason	11	Wican	SD	11	ivican	SD
Drug Question/Flu Shot	282	0.46	1.68	79	3.57	3.32
Drug Refill	163	0.27	0.99	59	2.76	1.83
Clinical Question	466	0.76	2.88	103	4.52	5.71
Result/Lab Order	155	0.25	1.27	64	2.42	3.22
DME / PT	80	0.13	0.84	28	2.86	2.8
Scheduling	303	0.49	1.89	85	3.56	3.87
Transitions	90	0.15	0.74	34	2.65	1.82
Thank You	123	0.2	1.05	58	2.12	2.79
Death	6	0.01	0.14	4	1.5	1.0

<sup>\*\*</sup>P value calculated using t-test for difference in number of EPP messages sent across medical conditions.

Admin/Billing/Non-Clinical	52	0.08	0.42	34	1.53	0.96
Coordination of Care	110	0.18	1.2	32	3.44	4.09
Request for Phone Call	8	0.01	0.13	7	1.14	0.38
All Messages	1,254	2.04	6.77	145	8.65	11.73

Overall, patients sent providers EPP messages primarily regarding clinical questions, drug/flu shot questions, scheduling matters, and coordination of care. Cross-sectional associations between purpose(s) of EPP message and whether EPP messages were primarily sent by patient or caregiver:

Table 13: EPP message type, by sender (Aim 4)

	Pa	tient	Caregiver		P Value*
	N	%	N	%	
Overall	62	-	82	-	
EPP Message Reason					
Drug Question/Flu Shot	34	54.8	45	54.9	1.000
Drug Refill	27	43.5	32	39	0.6111
Clinical Question	44	71	59	72	1.000
Result/Lab Order	31	50	33	40.2	0.3097
DME / PT	11	17.7	17	20.7	0.6776
Scheduling	39	62.9	46	56.1	0.4942
Transitions	11	17.7	23	28	0.1695
Thank You	22	35.5	36	43.9	0.3911
Death	1	1.6	3	3.7	0.6344
Admin/Billing/Non-Clinical	17	27.4	17	20.7	0.4287
Coordination of Care	14	22.6	18	22	1.000
Request for Phone Call	3	4.8	4	4.9	1.000

<sup>\*</sup>P value calculated using Fisher's exact test

We observed no differences in the EPP message type/content when comparing messages from patients and caregivers in this sample. Additionally, we looked at the mean number of messages by content that both patients and caregivers sent:

Table 14: EPP message type means, by sender (Aim 4)

	Pati	Patient		giver	P Value**
	Mean	SD	Mean	SD	
Overall	9.9	11.7	7.8	11.8	0.2812
EPP Message Reason					
Drug Question/Flu Shot	2.03	3.14	1.9	2.96	0.8000
Drug Refill	1.29	1.9	1.01	1.71	0.3589
Clinical Question	3.55	5.91	3	4.69	0.5360
Result/Lab Order	1.21	2.25	0.98	2.61	0.5729
DME / PT	0.52	1.72	0.59	1.63	0.8056
Scheduling	2.6	3.73	1.73	3.19	0.1369
Transitions	0.4	1.09	0.79	1.62	0.0881
Thank You	0.82	1.75	0.88	2.25	0.8682
Death	0.02	0.13	0.06	0.36	0.3544
Admin/Billing/Non-Clinical	0.4	0.8	0.33	0.8	0.5840
Coordination of Care	0.98	2.32	0.6	2.43	0.3372
Request for Phone Call	0.05	0.22	0.06	0.29	0.7647

We observed no differences in the number of EPP messages by type when comparing messages from patients and caregivers in this sample. For Aim 4, Part 3, we analyzed the mean phone call data:

# Aim 4, Part 3 (means of phone calls and EPP messages for patients & caregivers):

Table 15: EPP message type means, by type and sender (Aim 4)

	Phone		P Value*	EPP messages sent		P Value*
	encou	ınters				
	Mean	SD		Mean	SD	
Patient	8.9	11.1	0.6386	9.9	11.7	0.2812
Patient + Caregiver	9.9	13.0		7.8	11.8	

<sup>\*</sup>P value calculated using t-test

We observed no differences in the number of phone calls and EPP messages when comparing communications from patients and caregivers in this sample.

Aim 4, Part 4: categorize the content of the EPP messages sent by patients and caregivers to their providers to identify how the EPP is being used in this population in a six-month period:

Table 16: Patient (n<sub>P</sub>=62) & Caregiver (n<sub>C</sub>=82) Demographics, EPP Utilization (Aim 4)

Patient Age, mean (range)	87.9 (85-100)
Patient Sex, % female (n)	71.0 (44)
Patient Encounters, mean (12 months)	12.0
Patient EPP messages sent (6 months)	576
Mean (Range)	9.9 (1-66)
Quartile 1/ Quartile 2/ Quartile 3	2.0 / 4.0 / 8.5
Patient EPP login, mean (6 months)	43.1
Caregiver EPP login, mean (6 months)	27.3
Patient Medication Count, mean (range)	13.7 (2-30)

Overall, 1,254 EPP messages (n=576, mean 9.9) were sent by 62 patients and 82 caregivers (n=678, mean 7.8). Mean patient age was 87.9 years, 71.0% female, mean of 12 medical visits in past year and 13.7 active medications.

Table 17: EPP Message Content, by User (Aim 4)

	Patient, n (%)	Caregiver, n (%)
Clinical Questions	198 (25.0)	268 (27.2)
Scheduling	148 (18.7)	155 (15.7)
Medication/flu shot questions	118 (14.9)	164 (16.6)
Lab Orders/ Results	73 (9.2)	82 (8.3)
Medication refills	83 (10.5)	80 (8.1)
Appreciation for help	46 (5.8)	77 (7.8)
Care Transitions	14 (1.8)	76 (7.7)
Medical Equipment/Physical Therapy	30 (3.8)	50 (5.1)
Requests		
Administrative/Billing/Non-Clinical Issues	24 (3.0)	28 (2.9)
Patient Death	0	6 (0.6)

<sup>\*\*</sup>P value calculated using t-test for difference in number of EPP messages

Phone Call Requests	3 (0.4)	0
Coordination of Care**	54 (6.8)	0

<sup>\*\*</sup>p<0.05

Qualitative analysis revealed the following message topics by caregiver (c), patient (p): clinical questions ( $n_c$ =268, 27.2%;  $n_p$ =198, 25.0%), scheduling ( $n_c$ =155, 15.7%; $n_p$ =148, 18.7%), medication/flu shot ( $n_c$ =164, 16.6%; $n_p$ =118, 14.9%), lab orders/results ( $n_c$ =82, 8.3%; $n_p$ =73, 9.2%), medication refills ( $n_c$ =80, 8.1%; $n_p$ =83, 10.5%), appreciation for help ( $n_c$ =77, 7.8%; $n_p$ =46, 5.8%), care transitions ( $n_c$ =76, 7.7%; $n_p$ =14, 1.8%), medical equipment/physical therapy requests ( $n_c$ =50, 5.1%; $n_p$ =30, 3.8%), and administrative/billing/non-clinical issues ( $n_c$ =28, 2.9%; $n_p$ =24, 3.0%). Caregivers messaged about patient death (n=6, 0.6%) while patients requested phone calls (n=3, .4%) and messaged about coordination of care (n=54, 6.8%). Patients significantly (p<0.05) used the EPP more than caregivers for concerns about coordinating care between providers.

## **Discussion & Conclusions**

The results of this study provide important insight on the use of EPPs in older adult patient and caregiver populations and efforts that may be made to increase communication and use of this technology.

Offering EPP access for caregivers of older adult patients increased the information exchange between caregivers and health care providers at 2-weeks. Further research which includes a larger sample size and baseline data, is needed to investigate whether granting caregivers EPP usage facilitates the accuracy of outpatient medication reconciliation.

Older adults living in more than one setting at least one week during the year did not have caregivers who accessed the EPP more frequently in the 2-week follow-up period than those who did not report living in multiple settings. Overall, we did not find any correlation with predictors of EPP use for patients who live in multiple settings during the year.

Caregivers reported various barriers to EPP use including having challenges with using the correct password to log in, being too busy with other tasks to log in to the EPP, and having trouble reading the small print on the EPP interface. Caregivers also noted they did not log in because there was no pressing issue or need to, but when they did log in, they did not receive prompt responses from the health care providers, making them less likely to use the EPP in the future.

These findings may have implications for improvement of the EPPs to make them more user friendly and in turn, may help increase use by older adult patients and their caregivers. For instance, developers may be able to make the password retrieval simpler and increase the default font size on the EPPs. Additionally, these findings may help to remind healthcare providers to be timely in responding to their messages and requests submitted through the EPP to encourage continued use.

Patients 85 years and older readily utilized the EPP to facilitate medical care as observed in the six-month analysis. Both patients and caregivers used the EPP to message providers primarily

regarding: clinical questions, scheduling, medication/flu shot questions, and medication refills. When messages were examined by user and content, very few differences in EPP message content were observed. We also did not observe a difference between the numbers of EPP messages sent by caregivers of patients across medical conditions.

## **Significance**

This study is significant since to our knowledge, this is the first study to analyze the content of EPP messages sent by patients in the 85 year and older range and their caregivers to providers. The findings from these analyses may provide insight and feedback for health care providers to engage patients that are often not offered access to health IT and EPPs given assumptions about age and internet use.

# **Implications**

The results from this study show that EPP access for caregivers increased the information exchange between them and health care providers. We also observed in aim 4 that older adult patients (85+ years) readily utilized the EPP to facilitate their medical care in our sample. Thus, health care providers who want to engage their older adult patients and caregivers in their healthcare should offer both groups access to their EPP as there is evidence of use in this population. This is especially important since older adults, especially those 85 and older, are less likely to be offered EPP access given assumptions about technology use and preference. Providers may also consider providing proxy access to caregivers to reinforce continued patient-provider communication.

## **List of Publications and Products**

Ramirez-Zohfeld, V., Xiong L, Morse L, et al. (April 11, 2018). Characterizing older adult (≥85 years) and caregiver proxy utilization of electronic patient portals (EPIC Mychart). Presentation at the 2018 Society of General Internal Medicine Conference, Denver, CO.

Ramirez-Zohfeld, V., Xiong L, Morse L, et al. "Characterizing older adult (≥85 years) and caregiver proxy utilization of electronic patient portals (EPIC Mychart)" (In Submission)

#### References

- 1. http://www.markle.org/sites/default/files/ResearchBrief-200806.pdf. Accessed October 3, 2014.
- 2. Kaelber DC, Jha AK, Johnston D, et al. A research agenda for personal health records (PHRs). J Am Med Inform Assoc 2008 Nov-Dec;15(6):729-736.
- 3. Bates DW, Wells S. Personal health records and health care utilization. JAMA 2012 Nov;308(19):2034-2036.
- 4. Wuerdeman L, Volk L, Ferrari J, et al. Keeping patients active and current in a patient portal. AMIA Annu Symp Proc 2005;1160. PMID: 16779446.
- 5. Ruland CM, Brynhi H, Andersen R, et al. Developing a shared electronic health record for patients and clinicians. Stud Health Technol Inform 2008 Jan; 136:57-62.
- 6. Zickmund SL, Hess R, Bryce CL, et al. Interest in the use of computerized patient portals: role of the provider-patient relationship. J Gen Intern Med 2008 Jan;23(Suppl 1):20-26.
- 7. Siteman E, Businger A, Gandhi T, et al. Clinicians recognize value of patient review of their electronic health record data. AMIA Annu Symp Proc 2006;1101. PMID: 17238720.
- 8. Hess R, Bryce CL, Paone S, et al. Exploring challenges and potentials of personal health records in diabetes self-management: implementation and initial assessment. Telemed J E Health 2007 Oct;13(5):509-17.
- 9. Schnipper JL, Gandhi TK, Wald JS, et al. Design and implementation of a web-based patient portal linked to an electronic health record designed to improve medication safety: the Patient Gateway medications module. Inform Prim Care 2008;16(2):147-55.
- 10. Hassol A, Walker JM, Kidder D, et al. Patient experiences and attitudes about access to a patient electronic health care record and linked web messaging. J Am Med Inform Assoc 2004 Nov-Dec;11(6):505-513.
- 11. Houston TK, Sands DZ, Jenckes MW, et al. Experiences of patients who were early adopters of electronic communication with their physician: satisfaction, benefits, and concerns. Am J Manag Care 2004 Sep;10(9):601-608.
- 12. Delbanco T, Walker J, Bell SK, et al. Inviting patients to read their doctors' notes: a quasi-experimental study and a look ahead. Ann Intern Med 2012 Oct;157(7):461-470.
- 13. Ralston JD, Carrell D, Reid R, et al. Patient web services integrated with a shared medical record: patient use and satisfaction. J Am Med Inform Assoc 2007 Nov-Dec;14(6):798-806.
- 14. Krist AH, Woolf SH, Rothemich SF, et al. Interactive preventive health record to enhance delivery of recommended care: a randomized trial. Ann Fam Med 2012 Jul-Aug 2;10(4):312-319.
- 15. Wright A, Poon EG, Wald J, et al. Randomized controlled trial of health maintenance reminders provided directly to patients through an electronic PHR. J Gen Intern Med 2012 Jan;27(1):85-92.
- 16. Zhou YY, Kanter MH, Wang JJ, et al. Improved quality at Kaiser Permanente through e-mail between physicians and patients. Health Aff (Millwood) 2010 Jul;29(7):1370-1375.
- 17. Grant RW, Wald JS, Schnipper JL, et al. Practice-linked online personal health records for type 2 diabetes mellitus: a randomized controlled trial. Arch Intern Med 2008 Sep;168(16):1776-1782.
- 18. Bates DW, Wells S. Personal health records and health care utilization. JAMA 2012 Nov;308(19):2034-2036.

- 19. Sorensen L, Shaw R, Casey E. Patient portals: survey of nursing informaticists. Stud Health Technol Inform 2009;146:160-5.
- 20. Wald JS, Burk K, Gardner K, et al. Sharing electronic laboratory results in a patient portal--a feasibility pilot. Stud Health Technol Inform 2007;129(Pt 1):18-22.
- 21. Grant RW, Wald JS, Poon EG, et al. Design and implementation of a web-based patient portal linked to an ambulatory care electronic health record: patient gateway for diabetes collaborative care. Diabetes Technol Ther 2006 Oct;8(5):576-86.
- 22. Gandhi TK, Cook EF, Puopolo AL, et al. Drug complications in outpatients. J Gen Intern Med 2000;15:149-154.
- 23. Ellenbecker FS, Verney S. Nurses' observations and experiences of problems and adverse effects of medication management in home care. Geriatr Nurs 2004;25(3):164-170.
- 24. Gray MJ, Blough DK. Adverse drug events in elderly patients receiving home health services following hospital discharge. Ann Pharmacother 1999 Nov;33:1147-1153.
- 25. Aspden P, Wolcott J, Bootman L, et al; Institute of Medicine, eds. Preventing Medication Errors. Washington DC; National Academies Press; 2006.
- 26. Insel K, Morrow D, Brewer B, et al. Executive function, working memory, and medication adherence among older adults. J Gerontol B Psychol Sci Soc Sci 2006 Mar;61(2):102-107.
- 27. Starr J, McGurn B, Whiteman M, et al. Life long changes in cognitive ability are associated with prescribed medications in old age. Int J Geriatr Psychiatry 2004 Feb;19(4):327-332.
- 28. Gellad WF, Grenard JL, Marcum ZA. A systematic review of barriers to medication adherence in the elderly: Looking beyond cost and regimen complexity. Am J Geriatr Pharm 2011 Feb;9(1):11-23.
- 29. Tun PA, Lachman ME. The association between computer use and cognition across adulthood: Use it so you won't lose it? Psychol Aging 2010 Sep;25(3):560-8.
- 30. Boechler PM. Aging and On-line Learning. In P. Rogers, G. Berg, J. Boettcher, C. Howard, L. Justice & K. Schenk (Eds.), Encyclopedia of Distance and Online Learning (2nd ed.); 2008. Hershey, PA: Information Science Reference.
- 31. Boechler PM, Foth D, & Watchorn, R. Educational technology research with older adults: adjustments in protocol, materials and procedures. Educ Gerontol 2007;33(3):221-35.
- 32. Hatt WJ, Vanbaak EA, Jimison HB, et al. The exploration & forensic analysis of computer usage data in the elderly. Conference Proceedings: Annual International Conference of the IEEE Engineering in Medicine & Biology Society 2009:1216-9.
- 33. Baker NA, Rogers JC. Association between computer use speed and age, impairments in function, and touch typing training in people with rheumatoid arthritis. Arthritis Care Res 2010 Feb;62(2):242-50.
- 34. Lindquist LA, Pollack J, Go L, et al. Relationship of health literacy to intentional and unintentional non-adherence of hospital discharge medications. J Gen Intern Med 2012 Feb;27(2):173-8.
- 35. Weaver FM, Waters T. Patients' and caregivers' transition from hospital to home. Needs and recommendations. Home Health Care Serv Q 1998;17:27-48.
- 36. Insel K, Morrow D, Brewer B, et al. Executive function, working memory, and medication adherence among older adults. J Gerontol B Psychol Sci Soc Sci 2006 Mar;61(2):102-107.
- 37. Jensen RE, Chan KS, Weiner JP, et al. Implementing electronic health record-based quality measures for developmental screening. Pediatrics 2009 Oct;124(4):e648-54.
- 38. Bourgeois FC, Mandl KD, Shaw D, et al. Mychildren's: integration of a personally controlled health record with a tethered patient portal for a pediatric and adolescent population. AMIA Annu Symp Proc 2009:65-9. PMID: 20351824.
- 39. Resau LS. Obtaining informed consent in Alzheimer's research. J Neurosci Nurs 1995 Feb;27(1):57-60.
- 40. Kim S, Kim H, Langa KM, et al. Surrogate consent for dementia research: a national survey of older Americans. Neurology 2009 Jan;72(2):149-155.
- 41. Sunderland T, Dukoff R. Informed consent with cognitively impaired patients: an NIMH perspective on the durable power of attorney. Account Res 1996 Jun;4(3-4):217-26.

- 42. Arno PS, Levine C, Memmott MM. The economic value of informal caregiving. Health Affairs 1999;18(2):182-88.
- 43. <a href="http://www.aspenwsi.org/wordpress/wp-content/uploads/Profiles-of-the-Direct-Care-Workforce-and-PHI.pdf">http://www.aspenwsi.org/wordpress/wp-content/uploads/Profiles-of-the-Direct-Care-Workforce-and-PHI.pdf</a>. Accessed October 1, 2014.
- 44. Malone B, Langeland, KL. Boomers' prospective needs for senior centers and related services: a survey of persons 50-59. J Gerontol Soc Work 2011 Jan;54(1):116-30.
- 45. Lindquist LA, Tam K, Friesema E, et al. Paid caregiver motivation, work conditions, and negative outcomes among senior clients. Arch Gerontol Geriatr 2012 Sep-Oct;55(2):442-5.
- 46. Gure T, Kabeto M, Blaum C, et al. Degree of disability and patterns of caregiving among older Americans with congestive heart failure. J Gen Intern Med 2008 Jan;23(1):70-6.
- 47. Jenkins K, Kabeto M, Langa KM. Does caring for your spouse harm one's health? Evidence from a United States nationally-representative sample of older adults. Ageing Soc 2009 Feb;29(2):277-293.
- 48. Kim C, Kabeto, M, Wallace R, et al. Quality of preventive clinical services among caregivers in the Health and Retirement Study. J Gen Intern Med 2004 Aug;19(8):875-78.
- 49. Weiss C, Kabeto M, Langa KM. Differences in amount of informal care received by Non-Hispanic whites and Latinos. J Am Geriatr Soc 2005 Jan;53(1):146-151.
- 50. Langa KM, Vijan S, Hayward R, et al. Informal caregiving for diabetes and diabetic complications among elderly Americans. J Gerontol B Psychol Sci Soc Sci 2002 May;57(3): S177-S86.
- 51. Langa KM, Valenstein M, Fendrick AM, et al. Extent and cost of informal caregiving for older Americans with symptoms of depression. Am J Psychiatry 2004 May;161(5):857-863.
- 52. Langa KM, Fendrick AM, Flaherty K, et al. Informal caregiving for chronic lung disease among older Americans. Chest 2002 Dec;122(6):2197-2203.
- 53. Family Caregivers What They Spend, What They Sacrifice: The Personal Financial Toll of Caring for a Loved One (Minnesota, MN: Evercare and Bethesda, MD:NAC, 2007).
- 54. Johnson RW, Wiener JM. A Profile of Frail Older Americans and Their Caregivers. 2006. Washington DC: Urban Institute.
- 55. Lindquist LA, Cameron KA, Messerges-Bernstein J, et al. Hiring and training processes of agencies supplying paid caregivers to older adults. J Am Geriatr Soc 2012 Jul; 60(7):1253-9. PMID: 22724430.
- 56. Sady MD, Sander AM, Clark AN, et al. Relationship of preinjury caregiver and family functioning to community integration in adults with traumatic brain injury. Arch Phys Med Rehabil 2010 Oct;91(10):1542-50.
- 57. Goodman CC. Perceived social support for caregiving: measuring the benefit of self-help/support group participation. Journal of Gerontological Social Work 2008 Oct;16(3-4):163-175.
- 58. Northouse LL, Katapodi MC, Song L, et al. Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. CA Cancer J Clin 2010 Sep-Oct;60(5):317-39.
- 59. Lindquist LA, Tam K, Friesema E, et al. Paid caregiver motivation, work conditions, and negative outcomes among senior clients. Arch Gerontol Geriatr 2012 Sep-Oct;55(2):442-5.
- 60. http://www.caregiver.org. Accessed October 1, 2014.
- 61. <a href="http://www.aarp.org/relationships/caregiving/">http://www.aarp.org/relationships/caregiving/</a>. Accessed October 1, 2014.
- 62. http://www.nfcacares.org/. Accessed October 1, 2014.
- 63. http://caregivinghelp.org/. Accessed October 1, 2014.
- 64. Carney S, Koetters T, Cho M, et al. Differences in sleep disturbance parameters between oncology outpatients and their family caregivers. Clin Oncol 2011 Mar;29(8):1001-6.
- 65. Rongve A, Boeve BF, Aarsland D. Frequency and correlates of caregiver-reported sleep disturbances in a sample of persons with early dementia. J Am Geriatr Soc 2010 Mar;58(3):480-6.
- 66. Andersen R. A behavior model of families' use of health services. Research Ser 1968;25: University of Chicago.
- 67. Aday LA, Andersen R. A framework for the study of access to medical care. J Health Serv Res 1974 Fall;9(3):208-20.

- 68. Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? J Health Soc Behav 1995 Mar;36(1):1-10.
- 69. Andersen R, Newman JF. Societal and individual determinants of medical care utilization in the United States. Milbank Q 1973 Dec;51(1):95-124.